

York Neuroimaging Centre

How does social information and reward influence decision making and learning in adolescents?

Participant Information Sheet (Version 9)

Your child is invited to take part in a scientific project exploring why and when adolescents are socially influenced by peers. The project is funded by the University of York and is being carried out by researchers at the University of York.

In order to help you and your child decide if you would like to participate, we would like to provide you with some information about the research and what to expect if you choose to take part.

Please read the following carefully and ask any questions if you wish.

What is the purpose of the study?

This study is part of a larger project exploring how people learn and make decisions and how that changes as we age. In this study we are interested in how people use different types of information to make a decision and how that depends on the way the brain is developing across adolescence. Here we are also studying whether the types of information that people rely on when they make choices depends on what they have learned about those options and whether how people make decisions is related to differences in their mental well-being.

Why has my child been asked to take part?

We are looking to recruit 40 children aged 13 – 17 years old and 40 adults aged 25-29 years. Your child must be a fluent English speaker, right-handed and have normal or corrected to normal vision and hearing. Anyone diagnosed with a developmental condition, specifically: Dyscalculia, ADHD and Autism Spectrum Disorder. Additionally, any diagnosis of a mental health condition, specifically: diagnosed PTSD, Anxiety Disorder, Depression will also preclude participation. As the study involves an MRI scan, it will not be possible to include children that have metallic implants or dental braces. We are also unable to scan anyone who is pregnant.

Does my child have to take part?

No. It is up to you and your child to decide whether or not to take part. If you do, you will be given this information sheet to keep and will be asked to sign a consent form. Your child will be given an assent form to indicate that they would like to take part. Either you or your child are still free to withdraw any time and without giving a reason.

What will happen to my child if they take part?

The study involves one visit to the University of York.

Pre-visit screening - lasts about 15 minutes

The first part of the study involves speaking to the researcher in a video call with your child. No recordings of this call will be made. We will talk about the study and what will happen during your visit to the lab. We will go through some forms to make sure it is safe for you to be scanned. We will also show you a video of the scanner and what it looks like when someone is being scanned. We will also give you time to ask any question.

Lab visit - lasts about 2 hours

The lab visit will take place at the York Neuroimaging Centre (YNiC). During this visit, your child will have an MRI scan. MRI stands for Magnetic Resonance Imaging. MRI uses magnetic fields and radio waves to obtain highly detailed images of any part of the body such as the brain. It is a method used to take images of the brain, using a large magnet and radio waves. The MRI scanner is a big, white machine, with a hole where the magnet is. The MRI scan will be divided into two stages. In the first stage, your child may listen to music, while we take some pictures of the structure of their brain and brain activity while it is at rest. This lasts about 15 minutes. In the next stage, which takes about 40 minutes, we will ask your child to play a simple computer game in which they see different pictures on screen and make decisions about them. The pictures are simple images, such as different coloured shapes, that are likely to give different amounts of points if chosen. Your child will be in the MRI scanner for no more than 1.5 hours.

Outside the scanner we will ask your child to complete a short, age-appropriate questionnaire regarding their mental health (Revised Children's Anxiety and Depression Scale: [RCADS](#)), which will take no more than 5 minutes. Please click on the link above to view the statements included. Your child will be asked how often these statements happen to them. Examples of statements include: 'I worry about things', 'I have trouble sleeping', 'I have problems with my appetite' and 'I think about death'. We will also collect information about their age and sex.

Your child will also be asked to complete the adolescent version of the [Autism Quotient \(AQ\)](#) for subclinical autistic traits of Autism Spectrum Disorder (ASD). This involves answering 50 questions such as "I prefer to do things with others rather than on my own" and rating how much they agree with such statements on a 4-point scale from 'definitely agree' to 'definitely disagree'.

Additionally, they will be asked to complete the [ADHD self-report scale \(ASRS\)](#) for subclinical ADHD traits. This involves answering 18 questions such as "How often do you have problems remembering appointments or obligations." and rating how much they agree with such statements on a 5 point scale from 'Never' to 'Very often'.

What does the MRI scan involve?

Before entering the scanner room, appropriate screening for contraindications for MRI will be performed. Answering these questions correctly is essential to ensure participant safety. Your child will be asked to remove ANY metallic objects (including coins, jewellery, mobile phones and watches). The radiographer / researcher will position your child into the scanner and ask them to lie down on a comfortable bed. The scanning process generates intermittent loud buzzing / tapping noises. Ear-plugs or sound-attenuating headphones are provided. Cushions or supports may be used to make your child more comfortable and blankets are available if needed. A helmet will be placed over your child's head. Your child will then be moved into the scanner so that their head is positioned in the centre of the magnet. The radiographer will then leave the room. The radiographer / researcher can see your child and hear them throughout the procedure. Your child will be given a buzzer that they can press if they need assistance whilst in the scanner. It is very important that your child keeps their head as still as possible during the scan, as movement may introduce artefacts. If you or your child have any concerns, please talk to the researcher / radiographer before your child goes into the scanner.

What are the benefits of taking part in this research?

Participating in this research will assist us with gaining new insights into the mechanisms of social cognition and decision making and how it changes across development.

Is there a chance that the brain scan will detect something wrong with my child's brain?

Yes, neuroimaging research can detect brain anomalies (abnormal structural features). Such anomalies are uncommon (~3% of volunteers scanned). Most frequently, anomalies are benign and will not affect daily life or health prospects. More uncommonly (~1%), anomalies that are a risk to an individual's health are detected (figures were obtained from an article by Morris and colleagues published in the British Medical Journal, see <https://www.bmj.com/content/339/bmj.b3016.full>).

What are the potential benefits and harm that could arise from a brain anomaly being detected?

The chance finding of the anomaly may allow for action to be taken quickly that may benefit your child's health directly. In contrast, there is the possibility that a brain anomaly would have to be declared if you were to be seeking health insurance or other types of insurance for your child and could affect how insurance is provided to you. Knowing that a brain anomaly has been detected may also make you worry about your child's health in a way that you did not before. It is important to consider these issues in the context of volunteering for the study.

If no anomaly is detected, does my child have a 'clean bill of health'?

No. Almost all the research procedures undertaken at YNiC are not the same as the scans that are routinely used for clinical diagnosis. Therefore, you should not consider the absence of the detection of an anomaly as an indication of 'a clean bill of health'.

What procedures are used if an anomaly is suspected?

Under the circumstances that an anomaly is detected in your child's brain, the scans will be sent to a qualified Radiologist to give a clinical opinion. You and the principal investigator of the research project will be informed, in writing, that this has been done. Your GP will also be informed and will be supplied with the report given by the Radiologist. You will also be informed, in writing, that your GP has been sent the report on your child's scan. Your GP may contact you to discuss the appropriate course of action. Even if your GP does not contact you, you may wish to see him/her to discuss the report on the scan. You may give your permission for your child's data to be released for research purposes, by completing a data release form. You can read the policy on Diagnostic Imaging for further information if you have any concerns. It is important for you to weigh up the potential benefits and harm that may result from an anomaly being detected.

What are the possible disadvantages and risks of taking part?

Some participants may feel discomfort during the MRI scan, arising from, for example, claustrophobia, the high sound levels during scan, having to lie still for the duration of the experiment, or dis-equilibrium and/or mild nausea on entering or leaving a strong magnetic field. To minimise discomfort, ear-plugs or sound-attenuating headphones are provided, and cushions or supports are available. Your child will be given an alarm to press if they need assistance.

All procedures will be explained carefully to you and your child. If your child feels uncomfortable at any point during the study, we will stop the procedure. The study has been ethically approved by the University of York and is funded by the University of York. Each member of our research team has received an up-to-date enhanced Disclosure and Barring Service (DBS) check and is trained and experienced in carrying out research with children.

What will happen if my child doesn't want to carry on with the study?

If your child feels uncomfortable about any aspect of the study, please let the researcher know straight away. We will discuss their concerns with you and may be able to help. You or your child are free to withdraw from the study at any time without giving a reason. If you decide to withdraw, please tell the researcher.

On what basis will you process my child's data?

Under the UK General Data Protection Regulation (UK GDPR), the University has to identify a legal basis for processing personal data and, where appropriate, an additional condition for processing special category data.

In line with our charter which states that we advance learning and knowledge by teaching and research, the University processes personal data for research purposes under Article 6 (1) (e) of the UK GDPR:

Processing is necessary for the performance of a task carried out in the public interest.

Special category data is processed under Article 9 (2) (j):

Processing is necessary for archiving purposes in the public interest, or scientific and historical research purposes or statistical purposes.

Research will only be undertaken where ethical approval has been obtained, where there is a clear public interest and where appropriate safeguards have been put in place to protect data.

In line with ethical expectations and in order to comply with common law duty of confidentiality, we will seek your consent to participate where appropriate. This consent will not, however, be our legal basis for processing your data under the UK GDPR.

What type of data are collected or processed in this study?

We are collecting and processing two types of personal data (data that could potentially identify you) in this study. Personally Identifiable Information (PII) refers to data that can easily identify you or your child (for example, names, address, or date of birth). Research data refers to information your child provides as part of this study, for example answers to questionnaires and brain scans. Based on these data, it is often difficult to identify you or your child personally. We treat these two types of information differently, as outlined below.

How will you keep my child's data secure?

The University will put in place appropriate technical and organisational measures to protect personal data and/or special category data. The University is committed to the principle of data protection by design and default and will collect the minimum amount of data necessary for the project. In addition, we will use data in anonymised (all personally identifying information removed) or pseudonymised (using participant IDs) form wherever possible. No names will be used when the research is written up. We shall comply with the terms of the UK GDPR and other current data protection law.

What happens to my child's PII (identifiable information, such as my child's name and contact details)?

We shall store names and addresses (and any other type of information that can easily identify your child) separately from research data. Only one member of our research team will know the contact details of the participants. They are Dr MaryAnn Noonan. In addition, staff of the York Neuro-imaging Centre have privileged access to the computer systems and can link the names of participants with their data. Those people are under a professional obligation not to abuse this privilege. Pseudonymised data may be shared with our collaborators working in other institutions but the source data that could be used to identify individuals will never be shared. With the approval of the Research Ethics Committee of the York Neuroimaging Centre, other researchers may be allowed access to the pseudonymised data for use in research and teaching. Fully anonymised data may be made publicly available to allow full use of the research data, once the source data that can be used to identify individuals has been removed. Names and addresses will never be transferred internationally. If an anomaly is detected in your child's scan, staff at the York Neuroimaging Centre will have to share PII data with your GP, as described in the "***What procedures are used if an anomaly is suspected?***" section of this document.

What happens to my child's research data?

Research data will be stored separately from PII in an anonymous or pseudonymous format.

Conducting research is expensive and it relies on volunteers generously contributing their time. To make the most of your child's participation, we plan to retain their research data indefinitely and may use these data to answer research questions beyond those for which the data were originally collected. This may include combining research data from this study with research data from other studies in which your child has been involved.

In addition to potentially sharing research data with other researchers at the York Neuroimaging Centre, we also plan to share some research data more broadly with researchers across the UK and globally. This is important for the scientific process, so that other researchers have the opportunity to check our data and findings or to conduct new analyses.

In some cases, these research data can be shared in a fully anonymous format, with no connection to any personal data you provided. However, your child's data might be shared in pseudonymised format. In this case, the research data themselves are saved and shared with an anonymous ID code that cannot identify your child but there remains a link with your YNiC ID code *within* YNiC. This connection cannot be made by researchers outside YNiC.

When sharing MRI data, there is a small chance the research data themselves could identify your child. For instance, there is a very small chance that they could be identified (by themselves or another person) based on a brain scan. However, we will always take great care to minimise the chances of identification, for example by removing the face from an fMRI scan before sharing the data outside of YNiC.

In some cases, people will be required to agree to a "data usage agreement" in order to access research data. However, in other instances, data might be made fully "open", in which case we cannot control how that information is used.

[We plan to share the following types of research data:]

- Structural scan of the brain
- Scan of the brain activity at rest
- Scan of the brain activity during the task
- Age and sex

You should only agree to participate in this study if you have understood and consent to this re-use and sharing of research data.

Will you transfer my child's data internationally?

PII data will never be shared internationally. Research data may be shared internationally through open data sharing.

In cases where collaborators are based outside the University, pseudonymised or anonymised data may be shared using the University's cloud storage solution provided by Google, which means that data can be located at any of Google's globally spread data centres. The University has [data-protection compliant arrangements](#) in place with this provider. As stated above, we may make research data freely available through other platforms too.

How long will you keep my child's data?

Data will be retained in line with legal requirements or where there is a business need. Retention timeframes will be determined in line with the University's [Records Retention Schedule](#). When research data are shared publicly, they are retained indefinitely.

What rights do I have in relation to my child's data?

Under the UK GDPR, you have a general right of access to the data, a right to rectification, erasure, restriction, objection or portability. You and your child also have a right to withdrawal. Please note, not all rights apply where data is processed purely for research purposes. For further information see this [For further information, please see the University's guidance on rights requests.](#)

You can request to have your PII/YNiC account removed at any time by contacting YNiC staff. You can request to have your research data for this study deleted by contacting the project leader. It may not be possible to delete your research data if they are already processed and/or published.

What will happen to the results of the study?

We will analyse the results of the study and may present a summary of the data at conferences or in journal articles. The results may also be useful for gaining further funding to continue our research.

Who has reviewed the study?

This study was given a favourable ethical opinion by the Research Ethics Committee of the York Neuroimaging Centre.

What if there is a problem? How can I make a complaint?

If you or your child has a concern about any aspect of this study, you should ask to speak with the researchers who will do their best to answer your questions. They may be reached using the contact details given at the end of this sheet. If you or your child remain unhappy and wish to complain formally, you can do this through the complaints procedure of the University of York. Details can be obtained from the email address: registrar-and-secretary@york.ac.uk. If you are dissatisfied with the way the personal data has been handled please contact the lead researcher in the first case, or the University's Data Protection Officer at dataprotection@york.ac.uk. If you are unhappy with the way in which the University has handled your personal data, you have a right to complain to the [Information Commissioner's Office](#).

The York Neuroimaging Centre takes pride and care in ensuring that no harm, or risk of harm, occurs to participants in research. In the event that something does go wrong and your child is harmed during the research study and this is due to someone's negligence, then you may have grounds for a legal action for compensation against The University of York.

Who is organising and funding the research?

The study is being organised by Dr MaryAnn Noonan. They work in the Department of Psychology at the University of York. MaryAnn Noonan is a Lecturer in Psychology.

The study is being funded by The University of York.

Dr MaryAnn Noonan can be contacted at maryann.noonan@york.ac.uk and 01904 321037

Recompense

To recompense your child for taking part in this research they will be given £15 per hour, paid in gift vouchers, as a thank you for their participation. The research team will also pay reasonable expenses associated with travel as part of involvement in this research. To send you the vouchers we will ask for your or your child's email address. Your data will be shared with the administration team in the Department of Psychology so that they can process the payment. To reimburse travel expenses, we will collect your email address, address, name and bank details. These will be passed on to the admin team.

Support for parents and children

Some of the questions in this study ask about symptoms of depression and anxiety. If you, or your child feel that you need support with depression, anxiety or other mental health issues here are some sources of support:

- Your GP - GPs are the key route for accessing support and mental health care (including medication and/or psychological therapies) from the NHS
- A school nurse or mental health leader at your school
- TalkingSpace run psychoeducational courses, provide computerised and/or telephone based CBT and in some cases other options such as group CBT, mindfulness based therapies and individual therapy. www.talkingspaceplus.org.uk
- Samaritans offer a safe place to talk, and are particularly experienced in talking to people who have suicidal feelings. Website: www.samaritans.org
- For anyone under 35 having thoughts of suicide, HOPELineUK: <https://www.papyrus-uk.org/help-advice/about-hopelineuk>
- MoodGym at www.moodgym.anu.edu.au
- Living Life To The Full at www.livinglifetothefull.com
- Mood Juice at www.moodjuice.scot.nhs.uk
- York Family Information Service at 01904 554444 or fis@york.gov.uk
- Childline www.childline.org.uk